## CT General Assembly Insurance & Real Estate Committee Public Hearing

Testimony in <u>Support of SB 15, AAC Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections</u>.

By Lisa Williams 346 Hurlbutt Street Wilton, CT 06897 Submitted January, 29, 2015

Senator Crisco, Representative Megna and members of the Insurance & Real Estate Committee, my name is Lisa Williams. I am a parent and support SB 15.

The problem of not having health insurance for the coverage of PANDAS is twofold. First, parents, are forced to pay for treatment themselves with no insurance coverage. For many parents, this is a financial burden. Because PANDAS is often undiagnosed or misdiagnosed, children often go years with no treatment or the wrong treatment. The longer the child does not get the proper treatment, the harder and more expensive PANDAS is to treat.

The first line of treatment for PANDAS is an antibiotic which is a prescription most parents, pediatricians and insurance companies are familiar with. With insurance, this treatment will not be financially onerous for parents nor for insurance companies. It is the children that have not had treatment for PANDAS for a long time that would need the services of a specialist. The costs for the specialist and treatment like IVIG are exponentially more expensive than a supply of antibiotics.

For doctors, insurance coverage would provide them with the proper codes to diagnose and treat PANDAS children. As the insurance codes are communicated to the medical community, more doctors will be educated about PANDAS and would allow for quicker and more accurate diagnosis and treatment.

My son Brandt got PANDAS when he was two years old. He was not diagnosed with PANDAS but with Apraxia and autistic symptoms. He had

both Birth to Three services as well as was in Special Education preschool for two years when he turned three years old. These were very expensive to provide and were a great waste of time, resources and money. As a parent, I also paid for supplemental speech therapy through Norwalk Hospital. We spend money on a child therapist as well. His pediatrician, birth to three therapists, special education preschool teacher, speech therapist all missed what was really wrong with him. He suffered and our family suffered through those years. We cannot get that time back. We can not get money we spent on useless services that could been put away for his higher education. He could not talk, could not be potty trained, had frequent temper tantrums, rigidity, ADHD and OCD. By mandating that insurance companies pay for PANDAS, this disease will be more well known and considered when a child comes in to a doctor's office with PANDAS symptoms.